

Immunization Information Systems: National Vaccine Advisory Committee Progress Report, 2007

Alan R. Hinman, Gary A. Urquhart, Raymond A. Strikas, and the National Vaccine Advisory Committee

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This article summarizes principal findings and recommendations of the National Vaccine Advisory Committee 2007 Progress report on Immunization Information Systems (IIS). Considerable progress has been made in each of the four primary objectives of the IIS: ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry; ensure participation of all immunization providers and recipients; ensure appropriate functioning of registries; and ensure sustainable funding for registries. In addition, IIS use has been extended to deal with adolescent/adult immunization, preparedness, vaccine shortages, health information exchanges, and electronic medical records. Notwithstanding the progress, several factors impede smooth achievement of the 2010 goal. The three most critical are difficulties in exchanging information among different information systems, difficulties in exchanging information across state lines, and ensuring sustainable funding for registries. The committee has made a number of recommendations to address these issues.

KEY WORDS: child health, health information systems, immunization registries

The National Vaccine Advisory Committee (NVAC) is a legislatively mandated committee of 17 nonfederal employees charged with advising the Assistant Secretary for Health on ways to achieve optimal prevention of human infectious diseases through immunization as well as against adverse reactions to vaccines.¹

A 1997 NVAC report defined immunization registries (Immunization Information Systems, IISs) as “confidential, computerized information systems that contain information about immunizations and children.”² A Healthy People 2010 goal has been established to increase to 95% the proportion of

children younger than 6 years who participate in fully operational population-based immunization registries.³

The NVAC report (1997) enunciated the goal of a “nationwide network of community/state population-based registries that are capable of sharing information while maintaining privacy and confidentiality.” Four primary objectives were identified:

1. Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.
2. Ensure participation of all immunization providers and recipients.
3. Ensure appropriate functioning of registries.
4. Ensure sustainable funding for registries.

This article summarizes a 2007 NVAC report about IISs⁴ and describes progress since 2000 in each of the four areas. The 2007 NVAC report includes a full set of references to the progress mentioned in this article.

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Members of the National Vaccine Advisory Committee in February 2007 were Gary A. Freed, MD, MPH (Chair); Bruce G. Gellin, MD, MPH (Executive Secretary); Jon R. Almqvist, MD; Guthrie S. Birkhead, MD, MPH; Cornelia Dekker, MD; Mark Feinberg, MD; Jaime Fergie, MD; Lance Gordon, PhD; Alan R. Hinman, MD, MPH; Sharon G. Humiston, MD, MPH; Calvin Johnson, MD, MPH; Jerome O. Klein, MD; Mary Beth Koslap-Petraco, MS; Charles Lovell, Jr, MD; Trish Parnell; Andrew Pavia, MD; Laura E. Riley, MD; and Adele E. Young, PhD.

● Appropriate Protections of Privacy and Confidentiality for Individuals and Security for Information Included in the Registry

A great deal of attention has been paid to issues of privacy, confidentiality, and security—to the extent that these have not been major barriers to implementation of IISs. Minimum specifications for protecting the privacy of registry participants and the confidentiality of registry data were developed and approved by the NVAC in February 2000. Technical assistance has been provided to states to facilitate compliance with minimum specifications and to ensure that IISs that are regulated by Health Insurance Portability and Accountability Act (HIPAA) comply with requirements. The Centers for Disease Control and Prevention (CDC) has issued guidance on HIPAA and public health, and the American Immunization Registry Association (AIRA) has issued a resource document to help IISs be in compliance with HIPAA security standards. Every Child By Two, in collaboration with George Washington University, developed a model immunization information sharing statute.

The CDC's National Immunization Program (NIP, now the National Center for Immunization and Respiratory Diseases) provides support for immunization activities (including IIS) to 64 grantees (all 50 states, District of Columbia, Chicago, Houston, New York City, Philadelphia, San Antonio, Puerto Rico, Virgin Islands, and six Pacific Island countries or territories) through Section 317 of the Public Health Service Act. Privacy developments at the national level and their implications for IISs are being monitored by the CDC.⁵

One area in which there have been difficulties has been in the exchange of information with schools. The Family Educational Rights and Privacy Act (FERPA) provides, "Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record." Interpretations of FERPA vary among the states but generally have meant that the exchange of health-related information has been one way, with schools receiving health information about students from the public health and healthcare systems but not providing health information to those systems without prior parental consent.

● Participation of All Immunization Providers and Recipients

Progress in state or city grantee participation is shown in Table 1.

As of December 31, 2005, only one state (New Hampshire) reported having no efforts to develop and imple-

TABLE 1 ● State and city grantee participation^a

	2000	December 31, 2005
Children younger than 6 participating (ie, have two or more doses included)	21	56
Public provider sites participating	38	75
Private provider sites participating	19	44

^aValues given are percentages.

ment an IIS. Nine states and New York City reported more than 95 percent of children younger than 6 participating in IISs (Figure 1); 23 states and New York City reported more than 95 percent of public immunization provider sites participating; and 5 states and the District of Columbia reported more than 95 percent of private immunization provider sites participating in IISs. In a 2005 survey by America's Health Insurance Plans, 85 percent of health maintenance organizations and preferred provider organizations responding reported that they were currently sharing information with an existing immunization registry in their service area/state. The AIRA and Every Child By Two have developed a practical guide to partnering with health plans.

An IIS can readily generate reminder/recall messages, although many providers at the local level are not yet using this functionality. The American Academy of Pediatrics has recently issued a new policy statement on IISs that, in summary, states that it

continues to support the development and implementation of immunization information systems. . . . Pediatricians and others must be aware of the value that immunization information systems have for society, the potential fiscal influences on their practice, the costs and benefits, and areas for future improvement.⁶

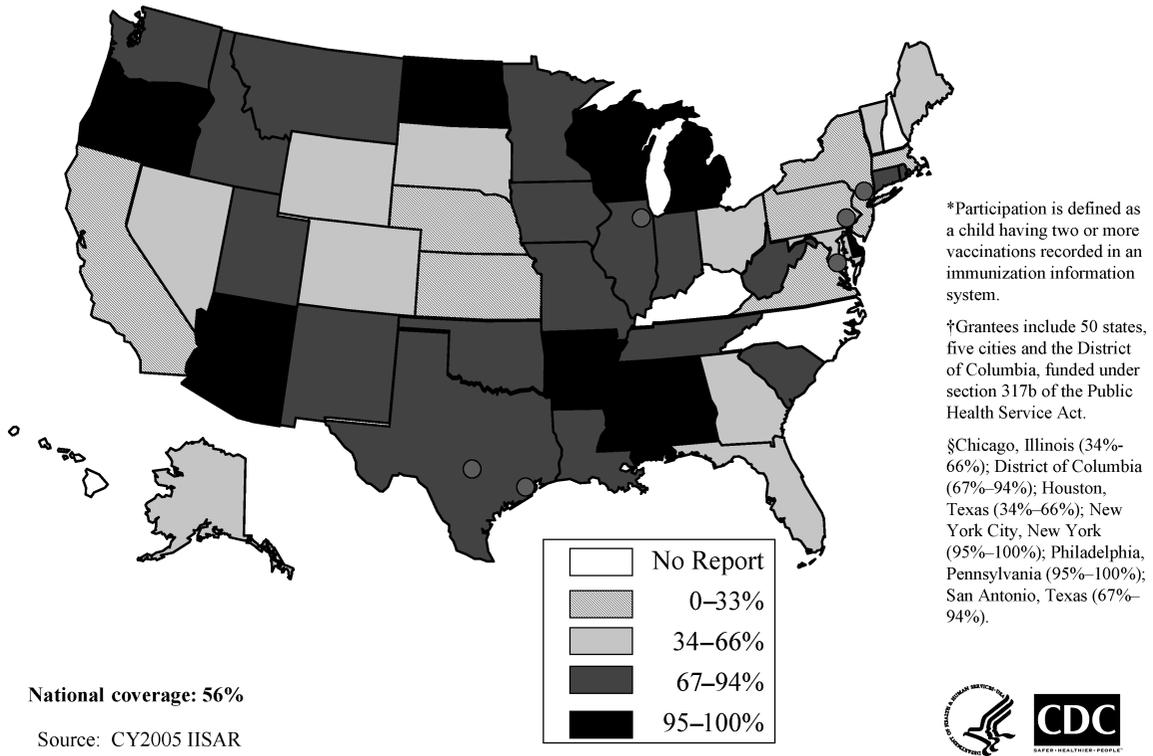
In its new *General Recommendations on Immunization*, the Advisory Committee on Immunization Practices states, in part:

IIS are a critical tool that can increase and sustain increased vaccination coverage by consolidating vaccination records of children from multiple providers, generating reminder and recall vaccination notices for each child, and providing official vaccination forms and vaccination coverage assessments. A fully operational IIS also can prevent duplicate vaccinations, limit missed appointments, reduce vaccine waste, and reduce staff time required to produce or locate vaccination records or certificates.⁷

● Appropriate Functioning of Registries

Minimum functional standards for immunization registries were developed by a Technical Working Group in 1997 and adopted, in slightly amended form, by the NIP in 2001. These standards have been used as the

FIGURE 1 ● Percentage of children younger than 6 participating^a in a grantee^b Immunization Information System—United States and six cities,^c December 31, 2005. Adapted from National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, Atlanta, Georgia.



basis for further development and implementation of IISs. To address newer uses of IISs, it may be necessary to expand the core dataset endorsed by the NVAC in 1995.

To stimulate improved performance and functionality of IISs, in 2006 the CDC/NIP required detailed business plan applications for IIS funding through Section 317. The plans summarized operational and financial objectives and indicated how the objectives were to be achieved.

The NIP established a Technical Work Group to develop approaches to objectively measure IIS performance against the 12 registry functional standards as a step toward certification of IISs. The work group developed a set of proposed evaluation criteria and pilot tested them in three volunteer sites. However, ongoing efforts including large-scale rollout and implementation of IIS certification have been delayed.

An important aspect of ensuring appropriate functioning of registries has been the activities of the AIRA. The AIRA is a membership organization to promote the development and implementation of immunization registries as an important tool in preventing and controlling vaccine-preventable diseases. It provides a forum through which registry programs, interested organizations and individuals and communities com-

bine efforts and share knowledge that promote registry activities as a resource for IISs and immunization programs. Useful AIRA products are available at www.immregistries.org.

In 2005–2006, of the 62 CDC grantees with (or developing) IISs, 19 were using software developed by the grantees themselves. The state of Wisconsin contracted with Electronic Data Systems for the applications development of the Wisconsin Immunization Registry (WIR) and has provided the WIR software to 12 entities. Scientific Technologies Corporation (STC) provides software to nine. Thus, 21 of 62 IISs are using software based on the WIR product or STC.

IISs have demonstrated their utility in improving immunization coverage, supporting vaccine safety, increasing timeliness of immunization, helping providers reach coverage goals, studying effectiveness and efficiency, and keeping managed care records up to date. A list of articles about IISs published in 2001–2006 is found in the NVAC report.⁴

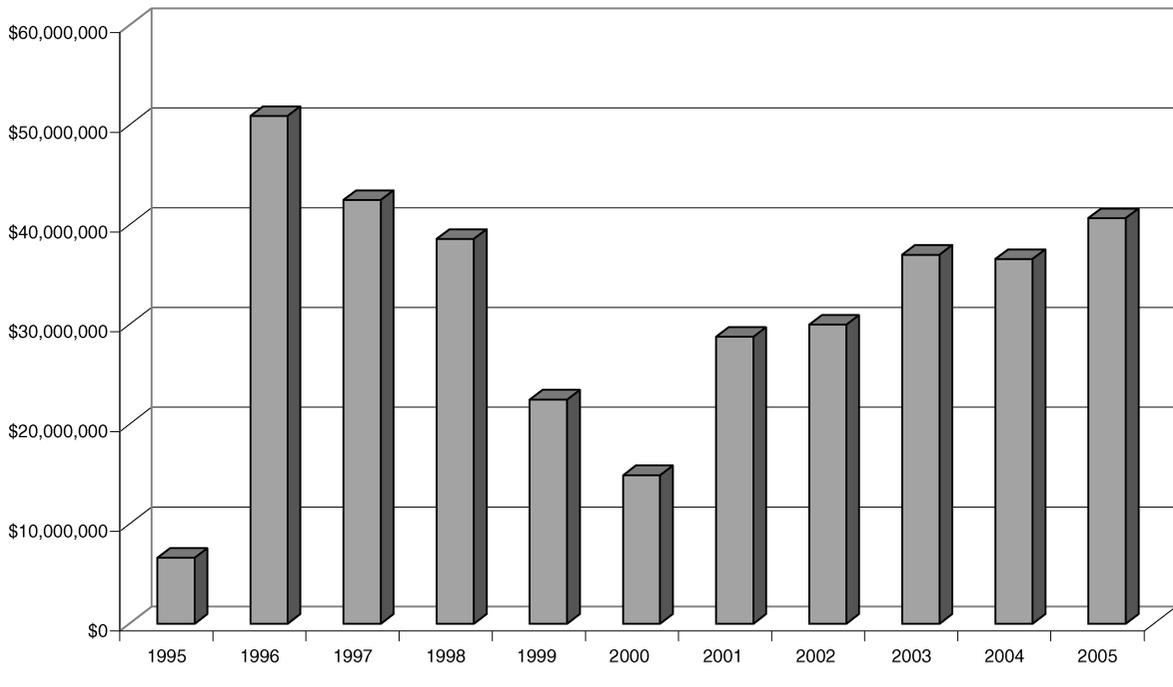
● Sustainable Funding for Registries

The level of federal support for IISs declined in the late 1990s and reached a low of approximately \$12 million



FIGURE 2 ● Funding for estimated Section 317 and VFC grant awards for Immunization Information System, 1995–2005. Adapted from National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, Atlanta, Georgia.

**Estimated 317 and VFC Grant Awards for Immunization Information Systems
1995–2005**



Source: CDC National Center for Immunization and Respiratory Diseases

in 2000 (Figure 2). Estimated funding in fiscal year 2005 was approximately \$40.6 million, about the same as in 1997. This total includes funding from Section 317 and from Vaccines for Children (VFC) operational funds (~29% of the total). Although overall funds for Section 317 have been increasing, they are having to cover substantially greater increases in funding needs as new vaccines are introduced and other unexpected immunization program demands arise (eg, Hurricane Katrina, planning for pandemic influenza). As is true with Section 317 funding, VFC operational funding is subject to annual appropriations, and is not an entitlement as is VFC vaccine purchase.

Funding sources for the 56 state or city grantees in 2005 are quite varied: 50 receive support from Section 317 funding, 27 from state/local sources, 10 from the Centers for Medicare & Medicaid Services, 11 from other federal sources, 7 from emergency preparedness funds, 7 from private sources, 3 from nonprofit organizations, and 2 from other sources.

Medicaid funding to support the development of IISs became available during 2000, but despite strong efforts to promote the development of applications for funding, only 10 immunization program grantees were successful in receiving funds during fiscal year 2005.

Financial support for IISs from health plans and insurers has had limited success to date. Almost 40 percent (22/56 state or city grantees) now report child participation levels of 80 percent or more and some health plans have started paying providers incentives of up to \$250 for each child with a completed immunization history in an IIS. If this practice can be promoted further, health plans will get their Healthcare Effectiveness Data and Information Set reports for much less cost, immunization coverage increases, providers get incentives to submit data, and completeness of immunization histories in an IIS improves.

Cost studies of IISs carried out before the 2001 NVAC report suggested an annual cost of \$4 to \$5 per child. Since that time, registries have matured and are increasingly Web based, so operational costs may be lower than originally estimated. A recent study assessed the costs in a sample of 24 IISs around the country, stratified by functional status, number of children enrolled, and whether the IIS had been developed as an independent system or was integrated into a larger system. The estimated annual cost per patient record ranged from \$0.09 to \$10.30 in operating the IIS. Overall, this cost was highly sensitive to local providers participation. The authors estimated that an additional \$75.6 million

would need to be allocated nationwide over the next 5 years in order to achieve the Healthy People 2010 goal of 95 percent participation in the IIS.

There has not been a specific IIS grant program enacted, as recommended by the NVAC in 2001.

● Newer Uses of IISs

Newer uses of IISs include their use in response to emergencies (including pandemic influenza, bioterrorism, or hurricanes),^{8,9} monitoring the impact of vaccine shortages, monitoring uptake of new vaccines, and linking to other health information systems. Examples of these are given in the full NVAC report.

IISs and interoperability with other health information systems/health information exchanges

IISs are among the most mature public health information systems that bridge the public health/clinical care divide. However, as long as they serve the single purpose of monitoring immunizations, their utility will be limited. Since 1999–2000, efforts have been supported by the Robert Wood Johnson Foundation and the Maternal and Child Health Bureau of the Health Resources and Services Administration to integrate IISs with other child information systems, notably vital registration, newborn dried bloodspot screening, and early hearing detection and intervention.^{10,11} Twenty-one states have been funded and are at varying stages of integration. In this context, integration refers to the integration of information as it is presented to the user, not to the background hardware or software. A variety of different approaches are being used to accomplish the integration.

At the national level, the Office of the National Coordinator for Health Information Technology has published a Framework for Strategic Action in delivering consumer-centric and information-rich healthcare. In 2004, the president has stated that “within 10 years, every American must have a personal electronic medical record.”¹² Health information exchanges (HIEs) are being established around the country to provide a means of sharing health information among healthcare providers, healthcare institutions, and health departments. IISs should play major roles in the design and implementation of these exchanges.

● Conclusions

Considerable progress has been made since the NVAC’s 2001 IIS progress report. IISs have demonstrated their effectiveness in improving immunization services and immunization coverage. They have also demonstrated

their worth in dealing with vaccine shortages and coping with disasters. They will be important components of addressing pandemic influenza or other threats and should play major roles in the emerging HIEs. Most IISs now have the ability to accept information on persons of all ages.

More than one half of the nation’s children are now participating in population-based IISs, and it appears possible to achieve the 2010 objective. However, significant challenges remain, including ensuring both sustainable funding for IISs and that IISs will be able to communicate with each other and with other information systems, including electronic medical records (EMRs) and HIEs.

● Recommendations

1. Ensure appropriate protections of privacy and confidentiality for individuals and security for information included in the registry.
 - i. Continue to ensure that IISs comply with HIPAA and other applicable laws/regulations governing privacy, confidentiality, and security, for example, Public Health Information Network standards.
 - ii. US Department of Health and Human Services should work with the Department of Education to ensure that FERPA does not impede the sharing of immunization information among schools, healthcare providers, health departments, and IISs.
 - iii. Federal legislation to establish a minimum set of standards and regulations for inter-state sharing of immunization data would be very helpful.
2. Ensure participation of all immunization providers and recipients.
 - i. IIS research and evaluation activities should be conducted to incorporate healthcare providers perspectives and needs into IIS development.
 - ii. Ensure appropriate IISs that are useful to all providers, both public and private.
 - iii. IIS performance measurements should be developed that demonstrate IIS value to all providers, both public and private.
 - iv. Continue to pursue partnership opportunities with professional organizations and other key stakeholder groups for collaboration on strategies to bring IISs into provider practices to include incentives for participation.
 - v. Ensure recipients/parents have easy access to their IIS immunization information.

3. Ensure appropriate functioning of registries:
 - i. Finalize and implement the approach to certification of IISs by promoting third party evaluation of IIS functionality, performance, and data quality assessment.
 - ii. Resolve remaining issues on exchange of information between IISs.
 - iii. Promote integration of IISs with EMRs, other health information systems, and HIEs.
 - iv. Promote the expansion and utility of IISs. One such expansion might be to include persons of all ages in an IIS.
 - v. Promote the continued development, implementation, and maintenance of standards pertaining to immunization registries
 - vi. Promote the central role of IISs in response to pandemic influenza or other public health emergencies.
 - vii. Encourage further evaluation and feasibility studies that use IIS data to support national vaccination coverage data needs.
 - viii. Promote enhanced immunization program management by analysis and use of IIS data for program evaluation, quality control, and assessment to meet state and local needs.
 - ix. Collaborate with Office of the National Coordinator on Health Information Technology to ensure IIS reporting standards are incorporated into EMRs that receive federal funds or that are certified by the National Coordinator on Health Information Technology.
4. Ensure sustainable funding for registries.
 - i. Ensure sustaining funding for IISs:
 - Continue and increase support for IISs through the 317 programs
 - Increase use of VFC operational funds
 - Increase support from the Centers for Medicare & Medicaid Services
 - Intensify discussions with insurers/health plans urging them to provide support for IISs (eg, \$5/year per person covered)
 - Develop a 5-year \$60 million/year grant program to support further development and initial operation of IISs (this could be

handled through a targeted increase in 317 funding).

- ii. Continue to update and expand studies of costs and benefits of IISs.

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